

Sexual dysfunction in women with type 1 diabetes in Norway: A qualitative study of women's experiences

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Abstract

Aim: The aim of this study was to explore the experiences of sexual health and sexual challenges in women with type 1 diabetes (T1D).

Methods: We used a qualitative study design and conducted semistructured interviews with 15 women (26–57 years) with T1D. The participants were recruited based on their Female Sexual Function Index score that indicated sexual dysfunction. We used thematic analysis to analyse the data.

Results: We generated three themes, each with subthemes: (1) Diabetes is present at all times (subthemes: having diabetes is onerous, and diabetes affects the relationship with my partner); (2) various challenges related to sexual health (subthemes: experiencing reduced sexual desire and physical challenges, and challenges related to sexual health affect the relationship with my partner); and (3) diabetes may affect sexual function (subthemes: glucose levels and technical devices may have an impact on sexual function, and sexual health should be addressed in diabetes follow-up).

Conclusions: The women with T1D experienced different challenges related to their sexual health. The most common were reduced sexual desire, vaginal dryness and pain during intercourse. The study emphasizes the importance of addressing sexual health in diabetes follow-up to provide comprehensive health services to people with diabetes.

KEYWORDS

diabetes Mellitus, type 1, female sexual dysfunction, qualitative study, sexual health, women's health

1 | INTRODUCTION

Onset of type 1 diabetes (T1D) is more frequent during childhood or adolescence; therefore, the disease is usually present in several life stages.¹ Having diabetes can be mentally

demanding because it imposes a lot of responsibility and is associated with psychosocial challenges, often referred to as diabetes distress.^{2,3} T1D may also have a negative impact on men's and women's sexual health, and although sexual dysfunction in men with T1D is not yet completely understood, knowledge and research on sexual dysfunction in women with T1D is considerably more limited.^{4,5}

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We previously uncovered a near doubled risk of sexual dysfunction in Norwegian women with T1D compared with healthy controls.⁶ Accordingly, several studies have indicated a significantly higher prevalence of sexual dysfunction among women with T1D compared with healthy controls,^{7–13} but occurrence, types and risk factors are still unclear. There are many suggested causes for the increased incidence of sexual dysfunction in women with T1D, including autonomic neuropathy, decreased blood supply due to vascular damage and psychosocial factors.⁹

Sexual dysfunction in women can manifest as decreased lubrication and ability to achieve orgasm, dyspareunia and loss of libido.^{9,14} However, the results are divergent, and few studies exist.⁸ Thus, there is a need for further studies on this topic. In particular, there is a paucity of studies where the women themselves are given the opportunity to describe the challenges they experience in terms of sexual health. To address this, we conducted a qualitative interview study, aiming to explore the experiences of sexual health and sexual dysfunction in women with T1D. The women included in the study had reported sexual dysfunction on the Female Sexual Dysfunction Index (FSFI) in our previous cross-sectional survey.⁶

2 | PARTICIPANTS AND METHOD

2.1 | Study design

We used a qualitative study design with semistructured interviews to explore the participants' experiences of sexual health and sexual dysfunction.

2.2 | Setting and participants

In 2018–2019, a cross-sectional study of sexual dysfunction in women with T1D was conducted at the diabetes outpatient clinic at Haukeland University Hospital.⁶ The participants completed FSFI, a 19-item multidimensional measure of sexual function over the past 4 weeks with a scale score ranging from 1.2 to 36.0.¹⁵ Fifteen of 86 participants who met the criterion for female sexual dysfunction (FSD), defined as FSFI \leq 26.55, were randomly selected and invited to participate in a study to further explore a potential association between autonomic function and FSD. Before they came to the clinic for the tests, they were invited to participate in this interview study, as well. All the 15 invited consented to participate. The interviews were conducted when the women came to the clinic for the tests. The 15 women ranged from 26 to 57 years of age, seven of them were <40 years, two were 40–45 years, three were 46–50 years and three were above 50 years of age.

Novelty statement

- In this qualitative study, women with type 1 diabetes and sexual dysfunction explain in their own words the challenges they are facing related to their sexual health. The most reported challenges were reduced sexual desire, vaginal dryness and pain during intercourse.
- Although glucose levels and technical devices present specific challenges related to sexual activity, the women expressed uncertainty about the association between diabetes and their sexual problems.
- This study emphasizes the importance of addressing sexual health in diabetes follow-up to provide comprehensive health services to people with diabetes.

The duration of their diabetes ranged from 8 to 40 years and six of them used an insulin pump and 13 used a continuous glucose monitoring system (CGM). Four of the participants were not in a relationship, and 11 reported that they were in a relationship that had lasted between 2 and 30 years.

2.3 | Data collection

Initially, the author team developed a semistructured interview guide (Supplementary Table 1). The interview guide contains some main questions in addition to follow-up questions that were asked if the woman was unable to elaborate on the main question. Thus, the follow-up questions helped us to obtain more detailed descriptions. The first four interviews were initially intended as pilot interviews but did not lead to any changes in the interview guide and were therefore included in the analysis.

EKHK and MEHB, not previously involved in the diabetes outpatient clinic, conducted the individual interviews. The interviews took place in January 2021 at the diabetes outpatient clinic at Haukeland University Hospital, except for one telephone interview. The interviews lasted from 14 to 47 min and were audio-recorded and transcribed verbatim by the first and second authors.

2.4 | Data analysis

Thematic analysis according to Braun and Clarke¹⁶ was used to analyse the data (Supplementary Table 2).

The analysis team consisted of MEHB, EKHK, RBS and AH. MEHB and EKHK are sixth-year medical students. RBS is an experienced diabetes researcher with clinical experience as a nurse. AH is also an experienced diabetes researcher with clinical experiences as a diabetes nurse. She also has many years of lived experience with T1D.

In phase 1 of the analysis, the analysis team read and reread the data from the transcribed interviews. In phase 2, we individually highlighted ideas from the data set and generated codes. As part of phase 3, the analysis team participated in a workshop where the codes were discussed and organized into potential themes. The team had an open-minded, reflective discussion during this phase to avoid any pre-understanding affecting the results. The themes were again reorganized and reviewed in phase 4, making all data fit into codes and themes. Finally, in phase 5, we came to an agreement on the wording of the themes and subthemes.

2.5 | Ethics

This qualitative study was approved by The Norwegian Committee for Medical and Health Research Ethics (REK vest 2020/148231). The participants received both verbal and written information about the study before signing a written consent form. The audio files were transcribed soon after the interviews and deleted. The transcribed interviews were stored on a secure server at the responsible research institution. All authors have access to an encrypted version of the anonymous and transcribed interviews.

3 | RESULTS

The analysis generated three main themes: (1) Diabetes is present at all times, (2) various challenges related to sexual health and (3) diabetes may affect sexual

health. Each theme yielded two subthemes, as shown in Table 1.

3.1 | Diabetes is present at all times

The extent to which the participants experience being controlled by their diabetes, how it affects their everyday life and is a source of concern, is elucidated through the two subthemes: (a) Having diabetes is onerous and (b) diabetes affects the relationship with my partner.

3.1.1 | Having diabetes is onerous

The women described having diabetes as onerous in several ways. Diabetes was described as a condition that requires constant attention and management throughout the day and that it is time-consuming. Some mentioned that having diabetes requires a strict daily life characterized by rigid routines regarding food and activities, without much room for spontaneity, for example, related to sexuality. One woman described it this way:

There are too many routines. I miss the feeling and ability to be spontaneous without having to think about food, glucose level and activity. I feel that the diabetes is stealing my freedom in many ways. (Participant 1, 43 years)

Some women claimed that they did not take their diabetes monitoring seriously enough. The interviews revealed that a feeling of guilt for not thinking about diabetes all the time was common. However, it was also described that the biggest burden was to not be rewarded for the effort they put in:

It is onerous because even though I have a lot of knowledge and do the right things, I still cannot seem to do it right. It is annoying and

TABLE 1 An overview of the themes and subthemes gained from the semistructured interviews ($n = 15$)

Themes	Subthemes
1. Diabetes is present at all times	a. Having diabetes is onerous b. Diabetes affects the relationship with my partner
2. Various challenges related to sexual health	a. Experiencing reduced sexual desire and physical challenges b. Challenges related to sexual health affect the relationship with my partner
3. Diabetes may affect sexual health	a. Glucose levels and technical devices may have an impact on sexual health b. Sexual health should be addressed in diabetes follow-up

very mentally straining. The results do not match my effort. (Participant 5, 36 years)

Another described her main concern related to diabetes was the risk for chronic complications later in life:

I notice that I have concerns people my age should not have, especially regarding the future. What if I won't turn 50, what if my kids depend on me and I get complications due to my diabetes and there will be a lot of focus on having a sick mother. These are thoughts that I have, and I find it very mentally draining. (Participant 12, 30 years)

3.1.2 | Diabetes affects the relationship with my partner

A recurring theme among the women was that their partners were understanding and supportive. However, some still explained how diabetes affected their relationship including sex life, because the partner had to take part in the worries and challenges that the women experienced with their diabetes. One said:

And it also affects the relationship, of course, because the person you are going to live with must be involved in all the ups and downs. So, it affects a lot. (Participant 7, 50 years)

A few study participants explained how diabetes could be so all-consuming that it even affected larger life decisions, such as family planning. One woman stated:

It has probably affected it to the extent that my partner has wanted children for a long time, and I have been unsure if I would be able to handle it. (...) I have wondered if I will be able to take care of someone other than myself. So in that sense, diabetes has affected my relationship a bit, with regards to whether I wanted children or not, but I would say that we have always been able to talk about it. (Participant 14, 39 years)

3.2 | Various challenges related to sexual health

The various challenges the women experienced related to their sexual health can be understood in terms of the following subthemes: (a) Experiencing reduced sexual desire

and physical challenges and (b) challenges related to sexual health affects the relationship with my partner.

3.2.1 | Experiencing reduced sexual desire and physical challenges

Among the various challenges the women reported, reduced sexual desire was undoubtedly the most common, and for many, it had led to a decline in the frequency of sexual activity. Furthermore, several of the women explained that they rarely feel spontaneous sexual desire, and when sexual activity is initiated, it requires a lot of work to achieve desire. Lack of sexual desire was described by participants of different ages and life situations. One said:

There is a lack of desire. My husband does not believe me, that I have so little desire. But I kind of do not think about sex in everyday life. It's kind of the last thing I think about. (Participant 15, 34 years)

Another described:

There's no excuse really, the desire just isn't there. (Participant 11, 49 years)

Other major struggles that emerged throughout the interviews were the physical challenges experienced during sexual activity, such as pain, vaginal dryness and impaired sensitivity. Of these, vaginal dryness was the most common, and some stated that it was impossible for them to have sex without a lubricant. One said:

I experience not getting wet enough. I don't know if it is lack of desire or if it is something else. (Participant 6, 26 years)

Vaginal pain was also described among the physical difficulties related to the women's sexual activity. Some described the pain as persistent and always present during sexual activity, which could lead to them avoiding intimate situations. For others, the pain was not present all the time, but could vary according to situations such as menstrual cycle and degree of sexual desire. As one described:

It is not painful every time - not if I ovulate and manage to get aroused. Then it's fine. But since this is the exception, it often hurts. I get sore very quickly. (Participant 12, 30 years)

For one participant, the pain had persisted for a long time, and she described the consequences of this:

I feel like I'm not a sexual person anymore. Because it's a problem if I get sexually aroused and cannot do anything further because of the pain. (Participant 2, 55 years)

Decreased sensation was also reported as an issue in the women's sexual life. One said:

I can be aroused during the first part of the sexual act, and suddenly I feel nothing. It just stops, as if the whole vagina disconnects, and I have experienced that a lot in the last year. It is not like numbness in the vagina, but it loses sensitivity. My brain thinks it wants to, but my body is not always involved. (Participant 1, 43 years)

3.2.2 | Challenges related to sexual health affects the relationship with my partner

The sexual challenges described, particularly decreased sexual desire, entailed challenges in the relationship between partners. Some described that their low sex drive became a source of disappointment in their partner, which in turn could lead to the women feeling a lot of guilt. One said:

Considering that I do not so often feel like having sex, but my husband does - it becomes a typical topic of debate. (Participant 12, 30 years)

Lack of sexual desire also affected intimacy and thus the relationship itself for some of the participants. Some described their romantic relationship turning more into a friendship due to the lack of intimacy. One explained:

He becomes more like a friend and not like a boyfriend somehow. I try to work with myself, but it is difficult. I cannot force myself into wanting to have sex. (Participant 15, 34 years)

Even though the challenges related to sexuality affected the relationship for several of the participants, many described having understanding partners. Some even mentioned that the issues in their sexual life would be more important if they were not in a permanent relationship:

I think this would have been a greater problem if I was to change partners. I think one can be ashamed of having problems with something that should be so natural. So, I am eternally grateful to be with a person who is so understanding and knows what it's like. (Participant 14, 39 years)

3.3 | Diabetes may affect sexual health

The women described a degree of uncertainty about the relationship between diabetes and their sexual challenges, although they were sure that the blood glucose level could affect sexual activity in some circumstances. The women's experiences of the relationship between diabetes and sexual health were reflected through the two subthemes: (a) Glucose levels and technical devices may have an impact on sexual health and (b) sexual health should be addressed in diabetes follow-up.

3.3.1 | Glucose levels and technical devices may have an impact on sexual health

Some participants reported fear of getting severe hypoglycaemia during intercourse. One described having to abstain from sex for a period of time when she had varying glucose levels and frequent hypoglycaemia. Some also reported it as annoying having to monitor glucose levels in relation to sexual activity, or even having to interrupt intercourse due to hypoglycaemia. One described having to get acquainted with her body again, also in a sexual setting, after disease onset:

Maybe in the beginning, because then we were a little anxious - what if you get hypoglycaemia along the way, and you are not sure what it is - is it sexual arousal or is it hypoglycaemia? (Participant 8, 57 years)

A few participants described that, due to fear of hypoglycaemia, they try to maintain mild hyperglycaemia throughout the day, which in turn could lead to a feeling of nausea, lack of energy and general discomfort. Subsequently, these symptoms of hyperglycaemia could affect sexual health. One said:

When I have a high glucose level during sex, my mouth gets dry, and I get swollen. I have experienced weariness because I had such a high glucose level. (Participant 7, 50 years)

Technical devices, such as glucose monitors and insulin pumps, could be perceived as an obstacle during sexual activity. For some, this was a pure physical obstacle, and they were afraid of tearing it off, whereas for others, it was more of a mental challenge in that they had to constantly have a device attached and thus felt insecure about their body. However, they explained that technical devices became less of an obstacle the more they became familiar with the devices. One stated:

Not the glucose sensor I have now, but when I had the insulin pump, I felt it was a nuisance. My husband did not see it as bothering me at all, but I thought about it a lot. I was afraid I would tear it off during sex. (Participant 3, 54 years)

The ability to achieve an orgasm was also linked to glucose levels by some of the women:

Whether I get an orgasm or not depends on my glucose level. If I do not get an orgasm, I understand why when I see that my glucose level is over 15. There is a clear connection to the glucose level, there is no doubt about that. (Participant 14, 39 years)

One participant reported that her sex life had gotten worse after diabetes onset, without being able to pinpoint the reason. Some described that they viewed their diabetes as one part of everyday life, together with other stressful factors. It also became clear that an adequate glucose level throughout the day is essential for participants' sexual health. One said:

I don't know if it is diabetes directly, or just life in general. I think diabetes is a contributing factor. If I have had a slightly bad day regarding glucose levels, then sex comes pretty far down the priority list. (Participant 6, 26 years)

However, some women were unsure if there was any connection between diabetes and their sexual problems. Others were convinced that their diabetes had a direct impact on their sexual function, particularly challenges related to vaginal dryness:

Because of my diabetes, I get dry down there very quickly. So, I am absolutely dependent on lubricant, otherwise I get very dry very quickly. (Participant 10, 29 years)

The participants differed in age. Some of the women mentioned age as an alternative explanation to their sexual

challenges and suggested menopause as a crucial factor. One said:

I think maybe it's a natural development with less hormonal production. I have viewed it as more age-dependent than diabetes-dependent. (Participant 8, 57 years)

3.3.2 | Sexual health should be addressed in diabetes follow-up

The participants were almost unanimous that sexual health should be addressed during the annual check-up at the diabetes outpatient clinic. Some stated that having problems related to sexual health is taboo, and that they would find it a relief to know that they are not alone in this. In addition, some mentioned that it would be wise to provide information about this to women with T1D when they are young:

I think especially for those who get it when they are young. I see that there can be many challenges associated with that. For example, exploring your own sexuality when you have diabetes is an additional stressful factor. Then it would be very useful and safe for young women to be able to talk about it. (Participant 8, 57 years)

Some women said that it would be nice to be able to discuss the topic with their physician, but that it can be very difficult to address it themselves:

I would like more information, but I think it has been difficult to bring it up at doctor's appointments. It's hard to bring up, because it's a topic I'm not talking to anyone but my husband about. It is very close and intimate. (Participant 4, 50 years)

A few of the women were indifferent to whether sexual health should be brought up during consultation at the diabetes outpatient clinic, but none were opposed to it. The participants agreed that the topic should be addressed so that the patient can choose whether she wants to elaborate.

4 | DISCUSSION

This qualitative study allowed women with T1D to express the various difficulties and challenges they experienced related to their sexual health in their own words. Of the

sexual problems described, reduced sexual desire, vaginal dryness and pain during sexual activity were the most common. Also, previous survey studies have reported loss of libido, lubrication and arousal, pain and problems with orgasm as the most frequent challenges related to sexual health in women with diabetes.^{7,17}

The women described having T1D as mentally challenging as well as a significant stress factor in their everyday life, and some of them were convinced that diabetes-related distress had a negative impact on their sexual relationship with their partner. This is in accordance with the results from our cross-sectional study, which indicated a significant association between general diabetes distress and sexual dysfunction in women with T1D.⁶ The association between decreased sexual desire and diabetes distress is also highlighted in the study of Van Cauwenberghe et al.¹⁷ That study also indicated a significant correlation between sexual dysfunction and impaired psychological well-being in women with T1D. Our study indicated that having a stable and supportive partner seemed to be important in dealing with the sexual challenges. Several described tolerant and caring partners who they were able to talk to openly about the sexual health struggles. In general, it has been claimed that support from a partner has effects on health, especially by buffering the negative effects of stress on health.¹⁸ Accordingly, two previous systematic reviews of the literature have emphasized that social support and greater marital satisfaction are associated with better diabetes outcome.^{19,20}

The extent to which T1D has an impact on sexual health in women can be difficult to determine, and the extent to which the women in our study saw a direct connection between their sexual challenges and their diabetes varied. It is well known that high glucose levels can cause vaginal dryness.²¹ Several of the women explained vaginal dryness as an obstacle during sexual intercourse, leading to pain or even refraining from sexual activity. Although only three of the women in our study were >50 years old and further three were between 46 and 50 years, we cannot exclude being in or having undergone menopause as a cause of vaginal dryness in some of the women.²² Nevertheless, one participant in our study was convinced that her glucose level determined whether she was able to orgasm. Another described lack of vaginal sensation as well as dryness, which could indicate an autonomic neuronal dysfunction. Autonomic neuropathy is a well-known risk factor of sexual dysfunction in men.²³

Fisher et al.³ emphasized the importance of including the emotional aspects of T1D in clinical diabetes follow-up. The link between diabetes distress and sexual dysfunction and the results from this study support the need for sexual problems and dysfunction to be addressed

in diabetes follow-up. In a previous study, young adults with T1D highlighted the importance of being seen as a whole person, including all the emotional aspects of living with diabetes in diabetes follow-up.²⁴ In another interview study, the participants described diabetes follow-up as insufficient with marginal dialogue about everyday challenges with T1D.²⁵ Including sexual health as part of diabetes follow-up could give a more comprehensive health service for people with T1D.

4.1 | Strengths and limitations

In-depth interview is an appropriate way to obtain detailed information concerning personal experiences described in the informants' own words. An additional strength of a qualitative interview is the flexibility; it allows the interviewer to ask follow-up questions when needed. Furthermore, the selection of participants showed variety in age, diabetes duration and social situations. The age span of the participants offers insight into sexual health at different phases of life. The fact that some of the women had undergone menopause made it difficult to determine if the challenges were simply related to these hormonal changes or related to their diabetes. Information, for example, on depression and potential medications such as hormone replacement therapy could have been useful additional information to understand the study findings. In addition, we cannot exclude that including more or other participants could have yielded new or other findings. Nevertheless, we believe that the findings have some transferability to other women with T1D. Given the extent of the consequences that impaired sexual function has on women's lives, further research is needed to better understand the underlying mechanisms leading to sexual dysfunction.

4.2 | Conclusion

Women with T1D experienced different challenges related to sexual health. Reduced sexual desire, vaginal dryness and pain during intercourse were the most common. The study emphasizes the importance of addressing sexual health in diabetes follow-up to provide comprehensive health services to people with T1D.

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CONFLICTS OF INTEREST

None declared.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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